



## **DEPARTMENT OF HEALTH AND HUMAN SERVICES**

### **Health Resources and Services Administration**

#### **Meeting of the Advisory Committee on Heritable Disorders in Newborns and Children**

**AGENCY:** Health Resources and Services Administration (HRSA), Department of Health and Human Services.

**ACTION:** Notice.

**SUMMARY:** In accordance with the Public Health Service Act and the Federal Advisory Committee Act, this notice announces that the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC or Committee) scheduled a public meeting to be held Thursday, August 10, 2023, and Friday, August 11, 2023. Information about ACHDNC and the agenda for this meeting can be found on ACHDNC's website at <https://www.hrsa.gov/advisory-committees/heritable-disorders/index.html>.

**DATES:** Thursday, August 10, 2023, from 10:00 AM to 3:00 PM Eastern Time (ET) and Friday, August 11, 2023, from 10:00 AM to 2:00 PM ET.

**ADDRESSES:** This meeting will be held via webinar. While this meeting is open to the public, advance registration is required. Persons wishing to register to attend the meeting can do so via this link: <https://achdncmeetings.org/registration/>. Registration closes at 12:00 PM ET on August 9, 2023. Instructions on how to access the meeting via webcast will be provided upon registration.

**FOR FURTHER INFORMATION CONTACT:** Alaina Harris, Maternal and Child Health Bureau, HRSA, 5600 Fishers Lane, Room 18W66, Rockville, Maryland 20857; 301-443-0721; or [ACHDNC@hrsa.gov](mailto:ACHDNC@hrsa.gov).

**SUPPLEMENTARY INFORMATION:** ACHDNC provides advice and recommendations to the Secretary of Health and Human Services (Secretary) on the development of newborn

screening activities, technologies, policies, guidelines, and programs for effectively reducing morbidity and mortality in newborns and children having, or at risk for, heritable disorders. ACHDNC reviews and reports regularly on newborn and childhood screening practices, recommends improvements in the national newborn and childhood screening programs, and fulfills requirements stated in the authorizing legislation. In addition, ACHDNC's recommendations regarding inclusion of additional conditions for screening on the Recommended Uniform Screening Panel (RUSP), following adoption by the Secretary, are evidence-informed preventive health services provided for in the comprehensive guidelines supported by HRSA pursuant to section 2713 of the Public Health Service Act (42 U.S.C. 300gg-13). Under this provision, non-grandfathered group health plans and health insurance issuers offering non-grandfathered group or individual health insurance are required to provide insurance coverage without cost-sharing (a co-payment, co-insurance, or deductible) for preventive services for plan years (i.e., policy years) beginning on or after the date that is 1 year from the Secretary's adoption of the condition for screening.

During the August 10-11, 2023, meeting, ACHDNC will hear from experts in the fields of public health, medicine, heritable disorders, rare disorders, and newborn screening. Agenda items include the following:

- A presentation on health equity and newborn screening;
- An update on the Duchenne muscular dystrophy condition nomination and a potential vote on whether to move it forward to full evidence-based review, which, depending on the strength of the evidence, could lead to a future recommendation to add this condition to the RUSP;
- A presentation, discussion, and vote on an ACHDNC expedited review process for resubmitted condition nomination packages; and
- A potential presentation and vote on whether to consider Krabbe disease through the ACHDNC expedited review process described above.

The agenda for this meeting includes a potential vote on whether to recommend a nominated condition (Duchenne muscular dystrophy) to full evidence-based review. In addition, as noted in the agenda items, the Committee may hold a vote on whether to recommend a nominated condition (Krabbe disease) be considered through the ACHDNC expedited review process described above. Both votes may lead to a recommendation to add or not add these conditions to the RUSP at a future time.

Agenda items are subject to change as priorities dictate. Information about the ACHDNC, including a roster of members and past meeting summaries, is also available on the ACHDNC website listed above.

Members of the public will have an opportunity to provide comments on any or all of the above agenda items. Public participants may request to provide general oral comments and may submit written statements in advance of the scheduled meeting. Oral comments will be honored in the order they are requested and may be limited as time allows. Subject to change: members of the public registered to submit oral public comments are tentatively scheduled to provide their statements on Thursday, August 10, 2023. Requests to provide a written statement or make oral comments to ACHDNC must be submitted via the registration website by 12:00 PM ET on Wednesday, July 26, 2023. Written comments will be shared with the Committee, so that they have an opportunity to consider them prior to the meeting.

Individuals who need special assistance or another reasonable accommodation should notify Alaina Harris at the address and phone number listed above at least 10 business days prior to the meeting.

**Amy P. McNulty,**

*Deputy Director, Executive Secretariat.*

[FR Doc. 2023-14957 Filed: 7/13/2023 8:45 am; Publication Date: 7/14/2023]